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Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease

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Short title: Transition to adult care with inflammatory bowel disease

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ABSTRACT

Aim: It can be difficult for adolescents with inflammatory bowel disease (IBD) to make the transition from paediatric to adult care. We studied the outcomes of this process and defined what constituted a successful transition.

Methods: In 2008, 50 adolescents who attended our IBD transition clinic completed IBD-yourself, a self-efficacy questionnaire that we had previously developed and validated. We approached the subjects in 2014, two to six years after they transferred to adult care, and 35 agreed to take part in the current study. The outcome of transition was assessed by our newly developed Transition Yourself Score. In addition, the relationship between self-efficacy and the outcome of the transition was measured.

Results: The mean age of the patients was 21.8 years and 69% suffered from Crohn's disease. The transition process was successful in 63% of cases, moderately successful in 31% and failed in 6%. A successful transition was associated with effective use of medication and clinical remission at the time of transfer, but could not be predicted by self-efficacy. The Transition Yourself Score will be validated in future studies.

Conclusion: Nearly two-thirds (63%) of the adolescents who attended the IBD transition clinic had a successful transition to adult care.

KEY NOTES

- The definition of a successful transition from paediatric to adult care for patients with inflammatory bowel disease (IBD) is currently unknown.
- Using our Transition Yourself Score, which measures the outcome of transition, we found that 63% of the 35 patients who attended our IBD transition clinic had a successful transition.
- Self-efficacy did not seem to predict a successful transition, but clinical remission at transfer might.

Keywords: Inflammatory bowel disease, outcome, self-efficacy, transfer, transition

INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic relapsing inflammatory disorder of the intestine and manifests in adolescence in about 25% of cases (1, 2). As IBD is a lifelong disease, all paediatric patients will need to undergo the transfer to adult care. It is advisable to have a transition period to prepare patients and parents for the transfer, which refers to the actual handover of the patient to adult healthcare (3). A failed transition can adversely affect IBD related outcomes. It can increase non-adherence, non-attendance, hospitalisation rates and the need for surgery (4, 5). During the transition process, patients, their parents and the paediatric and adult gastroenterologist have specific tasks. Patients should acquire disease knowledge, autonomy and self-management (6, 7), while parents need to stimulate their child's independence and physicians should be knowledgeable about adolescents' developmental and health issues and prepare them for transfer (3). Transition programmes are designed to facilitate the transition process and increase knowledge and self-management (3, 8). Self-efficacy, a person's belief in their capability to organise and execute the actions required to deal with prospective situations, is thought to be a prerequisite for self-management (9, 10). It reflects self-care responsibility and has been shown to be a predictor of readiness to transfer (11). We previously developed and validated IBD-yourself, a specific IBD knowledge and self-efficacy questionnaire (12).

The optimal model for IBD transitional care is currently unknown, as is the definition of a successful transition, due to the scarcity of outcome research. We aimed to develop a tool, the Transition Yourself Score, to measure the success of transition. The Transition Yourself Score was applied to our IBD transition cohort to assess transition outcomes one year after transfer. In addition, we assessed the predictive value of self-efficacy for successful transition.

METHODS

Participants

In 2008, 50 patients from our IBD transition clinic participated in the validation study of the self-efficacy questionnaire, IBD-yourself (12). Of these, 35 gave informed consent to participate in the current study in 2014. Data on patient characteristics, disease type, treatment and outpatient clinic visits after transfer were retrieved from their medical records. The study was approved by the Medical Ethics Committee of the Erasmus Medical Centre, Rotterdam, The Netherlands.

IBD transition clinic

Adolescents aged 16 to 18 years old with IBD are seen at the outpatient clinic, which is located in the adult gastroenterology department. A multidisciplinary team, consisting of a paediatric gastroenterologist, a paediatric IBD nurse specialist, an adult gastroenterologist and a family therapist, discuss all patients before the start of the clinic. Patients visit the clinic at least four times a year, where they are seen by either the paediatric gastroenterologist or the paediatric IBD nurse specialist. Once a year the adolescent patients also meet the adult gastroenterologist, to get acquainted with the adult healthcare system. During clinic visits, both the nurse and doctors check for disease knowledge, self-efficacy and self-management skills. Around the age of 18, patients are transferred, either within our centre or to a hospital closer to home. The choice of the adult care team depends primarily on the complexity of the disease and secondarily on the patient's preference and where they live. As part of the routine care for all patients, irrespective of their disease severity, an appointment at the gastroenterology department is made within three to six months after transfer. At this time an extensive transfer letter, including the patient's medical history, is sent to the adult medical healthcare provider, with a copy to the patient.

Measurements

Transition Yourself Score

A score reflecting the outcome of the transition process was developed based on previous literature (13) and the outcome of a focus group meeting with IBD experts. The Transition Yourself Score was applied to participants one year after their transfer to adult care. The following items were rated: adherence to visits at the gastroenterology outpatient clinic, adherence to medication and qualitative evaluation of transition by the patient. A pre-test of the score with a representative group of 10 patients resulted in minor adjustments in the language.

We scored the adherence to the visits to the adult gastroenterologist by determining when the patients first appeared in the gastroenterology outpatient clinic. The percentage of missed scheduled outpatient visits within the first year was calculated by dividing the number of missed visits by the number of planned visits times 100. Rescheduled visits were not counted as non-attendance. Adherence to medication was determined by an adherence interview (Table S1) (14).

The interview contained 10 questions regarding medication use, missed medication and the experienced burden of the medication regimen. Patients could receive one point per question, with a maximum score of 10. Prescriptions for supplements, such as calcium or iron, were not included in the assessment of medication adherence. Low adherence was indicated by a score below six, medium by a score of six to eight and high by a score of eight or more. At enrolment, patients retrospectively graded the transition process on a 10-point scale, where one was very poor and 10 was excellent and these scores are recorded in Table 1. A total score below five indicated a failed transition, five or six was moderately successful and above six was successful. For the analysis we combined failed and moderately successful transition into the unsuccessful transition category, to reflect that improvements were needed in this group. We then compared those findings with the group of subjects who had a successful transition.

IBD-yourself

IBD-yourself is questionnaire that was previously developed and validated by our research group to explore knowledge about IBD and self-efficacy (12). It covers a number of domains, such as knowledge of IBD, diagnostic tests and medication use. Higher scores indicated higher overall levels of self-efficacy. As the number of questions could differ between patients, we just provided scores for each domain and no total score (Table S2) (12).

Clinical outcome one year after transfer

Data regarding relapses, disease related complications, admissions, surgery and pregnancies were retrieved from medical charts. Clinical relapse was defined as a relapse with a change in treatment strategy and, or, hospital admission.

Statistical analysis

Statistical analyses were completed using SPSS 18.0 for Windows (SPSS Inc, Chicago, USA). Significance was set at $p < 0.05$. Descriptive statistics were calculated as percentages for discrete data and medians with interquartile ranges (IQR) for continuous data. The chi-square test or Fisher's exact test was used to analyse categorical data. Correlation between the IBD-yourself and transition success was examined using Spearman's correlation coefficient and the Mann-Whitney U test.

RESULTS

Patients' characteristics

There were 35 adult patients who gave their informed consent, with a median age of 21.9 years and interquartile range (IQR) of 21.1-22.6. Of the 50 patients who took part in the 2008 study, two declined participation, one patient had died from a metastasised rectal adenocarcinoma due to Hermansky Pudlak syndrome and 12 patients had been lost to follow up. The clinical and

demographic characteristics are shown in Table 2, in the column total. The baseline characteristics of the 35 participants and 15 non-participants did not differ (data not shown), except for educational status. Of the non-participants, 80% had low educational status compared to 46% of the participants.

Outcome of transition at one year after transfer

Almost 90% of the patients visited the adult outpatient clinic in the first three to six months after transfer. In addition, 85% of the patients missed less than 10% of their outpatient visits in the first year after transfer. Most patients had medium medication adherence. Almost 70% of patients valued the quality of their transition as good, scoring it above a seven. When we used the total Transition Yourself Score, the transition was successful in 22/35 (63%) patients, moderately successful in 11 (31%) and failed in two patients (6%) (Table 1). A female patient with Crohn's disease failed the transition as she did not adhere to her medication, did not appear for her first appointment and presented more than one year after transfer in the emergency department with a clinical relapse. The other patient was a male patient with Crohn's disease who was transferred to a community hospital, but was lost to follow up after transfer.

Factors influencing outcome of transition

The clinical and demographic characteristics did not differ significantly between the group with successful and unsuccessful transition (Table 2). In the group with unsuccessful transition. 80% had active disease before their transfer to adult care and this approached significance ($p=0.052$). Female patients were more likely than males to have an unsuccessful transfer ($p=0.069$) (data not shown).

Relation between adolescent self-efficacy and successful transition

Spearman's correlation showed a significant correlation for the outcome of transition and the IBD-yourself domain that covered actual behaviour in medication use ($r=0.397$, $p=0.025$, $n=35$). In parallel, adolescents with a successful transition had significantly higher scores in the domain of actual behaviour in medication use (Mann Whitney U test: $U=60.0$, $z=-2.208$, $p=0.027$). As shown in Table 3, the scores of each IBD-yourself domain were divided in three groups, namely low, medium and high. A non-significant trend was seen in seven of the domains, with more patients having a high score in the successful transition group.

Clinical outcome at one year after transfer

Of the 35 patients, 10 patients (29%) had a relapse with clinical consequences in the first year after transfer. In 50% of these patients, the outcome of their transition was scored as either moderately successful or unsuccessful. In contrast, the transition was unsuccessful in 30% of patients without relapsing disease. No significant differences were found between the patients with or without relapse with respect to the outcome of their transition, therapy adherence and missed outpatient clinic visits (data not shown). Of the 35 patients, two underwent surgery, namely resection of the remaining colon after hemi-colectomy and resection of perianal skintags, one Crohn's disease patient developed a perianal fistula and received antibiotics and two patients developed a new extra intestinal manifestation (arthralgia). One patient became pregnant during anti-tumour necrosis factor treatment and delivered a healthy baby. None of the patients developed a malignancy during the study period.

DISCUSSION

Our study showed that in our IBD transition clinic, transition was successful in 63% of patients and moderately successful in 31% of patients. This modest success ratio indicates that there is room for improvement in our IBD transition strategy, both in general and in individual patients.

To our knowledge, only one previous study has described the outcome of transition in IBD care (15). Non-adherence rates were in accordance with our cohort, but higher rates of hospitalisation and disease complications were found after transfer. However, it is not clear at what point in the transition process this was assessed.

The outcome of transition has also been described in paediatric patients with other chronic diseases with success varying from 42-53% of patients (16-19). All these studies used a restricted definition of success, namely attending the first one or two visits in adult care. In our clinic the transition process starts early, at the age of 16, with early involvement of the adult gastroenterologist. This could explain the relatively higher rates of successful transition in our cohort compared to the cohorts of patients with other chronic diseases.

A scoring system for the outcome of transition in IBD is currently not available and we decided to develop such an instrument, the Transition Yourself Score. In 2015, a ranking list with key elements and indicators of successful transition in general was published (13). This list, together with previous literature, supports the elements of the Transition Yourself Score (13, 19-21). A qualitative evaluation by the patient was included because patient experiences are of essential importance, reflect continuity of care and should be taken into account (13).

We hypothesised that patient or disease related factors can influence the outcome of transition as well as the actual transition clinic. Our study indicated that female patients and patients with an active disease before transfer might be at risk for unsuccessful transition.

Unsuccessful transition may have serious consequences, such as non-adherence, hospitalisation or surgery. To our knowledge, there have not been any studies that have measured successful transition and correlated these to the clinical outcomes after transfer. Unfortunately, because of the limited size of our study, we were not able to do that either.

As discussed earlier, it has been suggested that self-efficacy is a prerequisite for self-management and transfer readiness (10, 11). Whitfield et al investigated self-efficacy in adolescent IBD patients and found that mean self-efficacy scores were higher in older patients, but not in patients with longer disease duration. Remarkably, communication with the doctor did not improve with age and about 80% of patients above 18 years of age reported that they were not independent when it came to disease management tasks (22). Unfortunately, this study did not assess if patients actually used the skills they claimed to possess. It could be that self-efficacy does not always correlate with actual behaviour. Our study showed that actual behaviour could be associated with transition success. Since the publication of the IBD-yourself, another self-efficacy scale for adolescents and young adults has been developed and validated, but studies using this scale have not yet been published (23).

This study had several limitations: the recruitment from a single centre, the retrospective nature and the small sample size limited the statistical analysis and generalisability. In addition, recall bias could have influenced the patients' recollections of the item quality of the transition process, since some patients participated several years after their transfer. Moreover, socioeconomic status was higher in participants than non-participants, which could have influenced the results of our study. Furthermore, the Transition Yourself Score needs to be validated and IBD-

yourself needs to be compared to other measures of self-efficacy for further validation. Lastly, the generalisability may be limited because of country specific transition approaches, but the general elements chosen to classify the success of transition can be tailored to each local situation.

CONCLUSION

Despite these limitations, this study was the first to evaluate the outcome of transition in IBD by using a new score, the Transition Yourself Score. We showed that, after attending our IBD transition clinic, 63% of patients had a successful transition. The IBD-yourself, which measured self-efficacy, did not predict a successful transition, which can question the importance of self-efficacy. We stress the importance of not only assessing self-efficacy or self-management, but also the outcome of transition and clinical disease course after transfer. If predictors for a successful transition can be identified, then transition programmes can be optimised. The Transition Yourself Score is a simple tool to assess the efficacy of transition programmes, but it needs to be validated.

Abbreviations: IBD: Inflammatory bowel disease, IQR: interquartile ranges

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Conflicts of interest: The authors have no conflicts of interest to declare

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Table 1. Transition Yourself Score

Items	Score	Frequency (n=35), n (%)
Time to first outpatient visit to adult gastroenterologist		
Unknown or after 12 months	0	1 (2.9)
After 6-12 months	1	3 (8.6)
Within 3-6 months	2	31 (88.6)
Non-attendance rates at outpatient clinic < 12 months after transfer		
>25%	0	2 (5.7)
10-25%	1	3 (8.6)
None / <10%	2	30 (85.7)
Medication adherence		
Low adherence	0	4 (11.4)
Medium adherence	1	17 (48.6)
High adherence	2	5 (14.3)
No medication prescribed ^A		9 (25.7)
Quality of transition (grade 0-10)^B		
< 5.5	0	0
5.5-7	1	11 (31.4)
>7	2	24 (68.6)
Total score:		
Failed transition	<4	2 (5.7)
Moderate successful transition	5 or 6	11 (31.4)
Successful transition	>6	22 (62.9)

^A These patients were given two points in total transition score. ^B as experienced by the transferred patient

Table 2. Patient characteristics

	Total (n=35)	Unsuccessful transition* (n=13)	Successful transition (n=22)	p value [§]
Age at diagnosis (years), (median, IQR)	13 (12-15)	14 (11.5-15.0)	13 (12.0-15.0)	0.875
Months in transition clinic before transfer (median, IQR)	13 (5-18)	10 (5.0-18.0)	13 (4.8-17.8)	0.811
Disease duration at transfer (median, IQR)	7 (7-10)	4.1 (3.0-6.9)	4.5 (2.9-6.1)	0.864
Years after transfer at inclusion in study				1.0
	<2 2 (5.7%)	1 (7.7%)	1 (4.5%)	
	2-4 20 (57.1%)	7 (53.8%)	13 (59.1%)	
	4-6 13 (37.1%)	5 (38.5%)	8 (36.4%)	
Gender (male), no (%)	15 (42.9%)	3 (23.1%)	12 (54.5%)	0.070
Disease type, CD, no (%)	24 (68.6%)	9 (69.2%)	15 (68.2%)	1.0
Medication at transfer [‡]				0.840
	Aminosalicylates 9 (25.7%)	3 (23.1%)	6 (27.2%)	
	Immunomodulators 25 (71.4%)	9 (69.2%)	16 (72.7%)	
	Anti-TNF 12 (34.2%)	5 (38.5%)	7 (31.8%)	
	Prednisone 2 (5.7%)	1 (7.7%)	1 (4.5%)	
	No medication 1 (2.9%)	0	1 (4.5%)	
Active disease during transfer	5 (14.3%)	4 (30.8%)	1 (4.5%)	0.052
Relapse within first year after transfer	10 (28.6%)	5 (38.5%)	5 (22.7%)	0.444
Educational level				0.467
	Low 16 (45.7%)	7 (53.8%)	9 (40.1%)	
	Medium 13 (37.2%)	3 (23.1%)	10 (45.5%)	
	High 6 (17.1%)	3 (23.1%)	3 (13.6%)	

‡ Some patients were prescribed more than one kind of medication ¥ moderately successful and failed transition § successful versus unsuccessful transition

Note: percentages are displayed as column percentages

Table 3. IBD- yourself and outcome of transition

Domains IBD Yourself	Unsuccessful transition (failed&moderate) (n=13), n (%)	Successful transition (n=22), n (%)
Self-efficacy in knowledge of IBD (n=35)		
12-14 points	2 (15.4%)	1 (4.5%)
15-17 points	6 (46.2%)	12 (54.5%)
18-20 points	5 (38.5%)	9 (40.9%)
Self-efficacy in knowledge of diagnostic tests (n=35)		
14-17 points	2 (15.4%)	4 (18.2%)
18-21 points	7 (53.5%)	8 (36.4%)
22-24 points	4 (30.8%)	10 (45.5%)
Self-efficacy in knowledge of medication (n=27)		
17-22 points	4 (40.0%)	4 (23.5%)
23-27 points	4 (40.0%)	6 (35.3%)
28-32 points	2 (20.0%)	7 (41.2%)
Actual behaviour medication use (n=32)*		
7-10 points	1 (10.0%)	2 (9.1%)
11-14 points	7 (70.0%)	3 (13.6%)
15-17 points	2 (20.0%)	17 (77.3%)
Self-efficacy in skills for independent outpatient clinic visits (n=35)		
12-20 points	2 (15.4%)	3 (13.6%)
21-28 points	5 (38.5%)	9 (40.9%)
29-36 points	6 (46.2%)	10 (45.5%)
Actual behaviour outpatient clinic (n=26)		
4-6 points	10 (90.9%)	9 (60.0%)
7-8 points	1 (9.1%)	6 (40.0%)
Self-efficacy in coping with IBD (n=34)		
5-8 points	1(8.3%)	1 (4.5%)
9-12 points	4 (33.3%)	6 (27.3%)
13-16 points	7 (58.3%)	15 (68.2%)
Self-efficacy in knowledge of transition process (n=31)		
32-42 points	3 (25.0%)	2 (10.5%)
43-52 points	4 (33.3%)	8 (42.1%)
53-62 points	5 (41.7%)	9 (47.4%)
Self-efficacy in transfer readiness (n=34)		
4-6 points	10 (76.9%)	14 (66.7%)
7-8 points	3 (23.1%)	7 (33.3%)

*p<0.05